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ABSTRACT

The booklet, written by the medical staff of a children's hospital, provides information for parents of children with juvenile rheumatoid arthritis (JRA). Arthritis is a swelling of the joint(s) in children and lasts for over 6 weeks (sometimes many years). Aspirin is the main medicine given for JRA, and it works not only to control pain but also, when given regularly, to control swelling. Activity is a key to overcoming stiffness (suggestions of play activities are listed by age group). Other activities which are a part of daily living, such as squeezing a washcloth, can become useful exercises. A special physical therapy program often makes getting the needed exercise less of a struggle between parents and children. Splints are sometimes recommended to aid weak or painful limbs. Extra care of eyes is needed as problems with children's eyes sometimes accompany JRA. A normal healthy diet is important and children suffering from JRA and their parents often face extra strain and problems in their social life. After JRA goes into remission it is important to follow up with examinations once a year for 4 to 5 years. (PHR)

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home care guide on juvenile rheumatoid arthritis (for parents)

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2

CONTENTS

1 / Introduction
2 / "So This Is JRA"
4 / Medication
8 / Fighting Stiffness
10 / Play Exercises by Age Groups
14 / Helpful Activities Done in Daily Living
18 / Special Exercise Program – Physical Therapy
19 / Splints
20 / Eye Care
21 / Diet
22 / Four Common Family and Social Problems
26 / When Your Child Seems to be Well Again

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jra

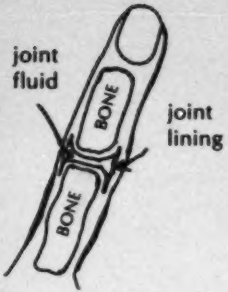
You were probably depressed, frightened and possibly angry when told that your child has Juvenile Rheumatoid Arthritis (JRA). These feelings are understandable and normal. The parents and medical staff who contributed to this booklet know that having a child with a chronic illness causes problems in almost every home. We hope the feelings and ideas of parents with children like yours will help you cope better with this illness.

If at any time you need help or information about JRA, the treatment, exercise, medicine, diet, behavior, and school or social problems please call:

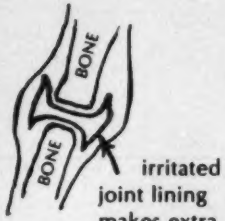
Day –
Night –
Weekends –

WORKING TOGETHER WITH YOU is the best way we and you can help your child..

4



Normal Joint



Arthritis Joint

"SO THIS IS JRA"

All Joints – in the body have a lining (synovium) with a little fluid inside the lining.

Arthritis Means – swollen, irritated, or inflamed joint. There are MANY causes of arthritis; JRA is only one.

JRA is – short for Juvenile Rheumatoid Arthritis. JRA is a type of arthritis in children that lasts more than 6 weeks and may last many years. Your child WILL PROBABLY OUTGROW the JRA and most children are NOT "crippled" by it. The cause is not known, and there is no known cure yet. But there are many things listed in this booklet that you and your child can do to help keep life as normal as possible.

Different JRA's? – Yes!

1. Some children get fevers, rashes, and many swollen joints
2. Some get only many swollen joints
3. Some get less than 4 swollen joints
4. Some get only one swollen joint

REMEMBER: Number of swollen joints DOES NOT = Chances of getting "crippling"

Patient:	Jane Smith
Age:	7 yrs.
Problem:	Swollen joints
Possible causes:	
	1. injury
	2. infection
	3. virus (flu)
	4. tumor
	5. disease in JRA family
	6. JRA

"It took so long to find out what was wrong!" – There are many diseases which can cause swollen joints or fevers or rashes. Because there is NO ONE TEST or X-ray to tell a doctor for sure that your child has JRA, he must first be sure your child does not have a problem which looks like JRA but really is not. It takes a long time (from 6 weeks to many months) to confirm the JRA diagnosis. There is probably nothing you could have done to get the diagnosis faster. Try NOT TO FEEL GUILTY about all the testing your child has had.

What to expect – We do not expect big changes in your family life or your child's life. We hope that you will be an active member of the team caring for your child.

Our goals are to help:

1. Your child continue normal play and school activities for his/her age.
2. Your child continue to grow as normally as possible.
3. The family structure and function stay as normal as possible.
4. The family and child learn care necessary to prevent "crippling" and keep the child active.
5. Keep good contact with your family doctor and school.

Please let us know what your goals are for your child, so we can work together to make a treatment plan that fits YOUR child's needs best.

MEDICATIONS

"Give my child plain old ASPIRIN?!"

YES,

is REAL medicine
BEST
SAFEST
MOST OFTEN USED medicine for JRA.

The different brands of Aspirin are all the same; buy whatever your drug store or supermarket carries.

BUT

NEVER USE IN PLACE OF ASPIRIN:

Tylenol	Liquid medicines
Anacin	"Arthritis strength" medicines
Bufferin	Excedrin
Datril	

Aspirin works – by getting into the blood and going to the joint linings. It helps protect healthy joints from getting swollen and reduces the swelling in irritated joints. The Aspirin is NOT being given ONLY to control pain.

Aspirin works – BEST if it is given faithfully 4 times a day. Missing even 1, 2 or 3 doses a week could delay improvement in the joint swelling. It may take as long as 3 months of taking the Aspirin every day before the joints show signs of getting better.

How many Aspirins? – JRA patients need more Aspirin to control the JRA than is needed to treat fever or headache. The doctor figures out the correct number of tablets by your child's weight and by blood tests to check the amount of Aspirin in the blood. For BEST blood test results take child for testing 2 HOURS AFTER ANY DOSE OF ASPIRIN.

Give Aspirin – with each meal and at bed time with a snack

Breakfast	Lunch	Supper	Bedtime
_____	_____	_____	_____

Allow at least 3–4 hours between doses.
Never give more than 4 adult size tablets at one time.
Read labels – never give your child another medicine that has "Salicylate" or "Aspirin" in it unless your arthritis doctor says it is OK.

Weight

= Right number Aspirin to give

"Aunt Alice said too much Aspirin is bad for my child's stomach." FALSE.

A. Children tolerate Aspirin much better than adults.

B. Also your doctor will be trying to prevent bad side effects by getting the Aspirin blood levels often whenever he changes the number of tablets your child takes.

C. You can help prevent trouble by watching for and CALLING IF your child gets:

1. rapid deep breathing when not exercising
2. stomach pain or vomiting after taking the aspirin
3. black or "tarry" bowel movements
4. "ringing" or "buzzing" in the ears
5. frequent nose bleeds
6. very sleepy or drowsy most of the day

It is important that an aspirin blood test be done BEFORE STOPPING the aspirin if at all possible. (A bad cold or the flu can cause many of the same signs.)

1 Adult Aspirin Tablet (325 mg) = 4 Baby Tablets (75 mg. each × 4)

Adult and Baby Aspirin are the SAME medicine. Many little children start to spit baby Aspirin after a few weeks. Parents can try crushing adult size tablets and mixing them with honey, jam, ice cream, sugar, applesauce, etc. The adult Aspirin this way might go down much easier and is MUCH CHEAPER.

Other medicines used in JRA treatment are gold injections, steroids, Indocin, and Tolectin, etc. If your child should need any of these your doctor would talk to you about what they do and their side effects.

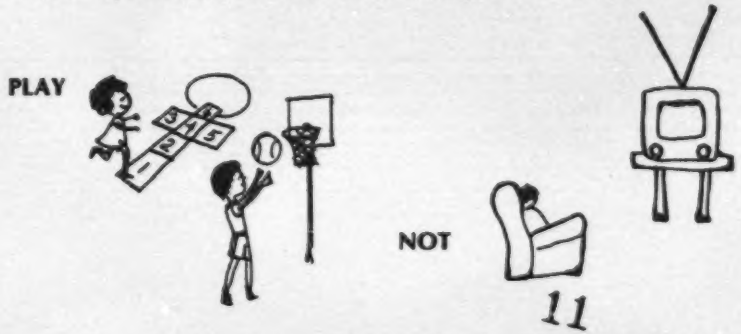
REMEMBER:
1. Give the right number of aspirin every day even if your child feels completely well. It is the aspirin that is helping your child feel this way.
2. Never change the amount of aspirin yourself.
3. Call if you have ANY questions about medicines.

FIGHTING STIFFNESS

"I'd Like to Cancel Mornings!" – It is common for the child with JRA to wake up stiff, moody, crying, in pain, or looking lazy. This stiffness may last a few minutes or several hours.

To help A.M. Stiffness:
1. Get Moving!
2. Warm bath or shower for 15–20 minutes
3. Sleep in a sleeping bag
4. Do not forget breakfast Aspirin dose

Fighting Stiffness takes MUSCLE – Lying or sitting to read or watch TV for many hours makes muscles weak, joints stiff, and can cause fixed joint deformities.



CHILDREN WITH JRA MUST STAY ACTIVE – How?

1. Allow your child to play as actively as possible. Using swollen joints carefully, so no pain is created WILL NOT hurt them. The next 2 pages will give you activity ideas.
2. Let your child help with light house chores – dishwashing, sweeping, bed making, pet feeding, etc.
3. Let your child dress, wash, feed HIMSELF – Of course things will move faster if you did them and it will be hard for any parent to watch a child struggle, but in the end it is better for your child's physical health AND mental health if you learn to let him (her) do daily tasks alone.
4. Try not to skip gym class.
5. Going out in bad weather (cold, rain) is NOT harmful.

"But I'm tired" – some children with JRS get tired easier than other children. If your child is tired allow a nap for 1–2 hours, but then he/she should get up and move around.

If there are joint deformities – or severe muscle weakness – special exercises will be prescribed and and shown to you during clinic visits.

12

REMEMBER:

Active play is the best exercise because it helps keep the muscles strong and the joints moving while it also makes your child feel normal and lets him forget the pain and difficult movement.

PLAY EXERCISES BY AGE GROUPS

Age 6 months to 4 years:

1. Playing in warm water with toys moves all joints and helps pain.
2. Toys that pull apart (pop beads) – to strengthen hands and arms.
3. Tickle bottoms of feet – to bend knees and hips.
4. Put plastic ring over ankle and leg – to bend leg to take it off.
5. Pushing and catching a balloon or soft beach ball – to strengthen arms.
6. Kicking a balloon or soft beach ball – to bend knees and strengthen legs
7. Reaching for toys over the head – to stretch shoulder joints.
8. Squeeze and roll play-dough – to strengthen hand and bend wrist.
9. Tricycle or toys to scoot – to move full leg and strengthen it.

Age 5–8 years:

1. Warm bath and playing with toys in the water – to move all joints and help pain.
2. Pieces of elastic to pull into funny shapes (Dental Dam is a thin elastic sheet that you can draw on and pull into funny shapes; get it at dental supply houses – to strengthen arms and hands.
3. Any crafts the child likes – usually strengthen and move joints of arms and hands.
4. Play-dough to squeeze and roll – to strengthen hand and bend wrist.
5. Tricycle or bicycle – to move leg in many positions.
6. Swimming classes – total body exercise.

13

Age 9–13 years:

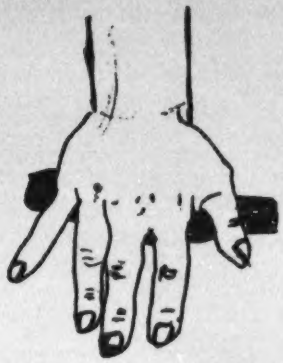
1. Swimming – total body exercise.
2. Crafts – usually strengthens and moves joints of arms and hands.
3. Bicycling – gives leg joints movement and strengthens leg muscles.
4. School activities (INCLUDING gym) – total body movement.

   *Ask your doctor if your child should play "contact" sports or do head stands.
5. Hitting and catching soft balls or volley balls – arm strength.
6. Ballet – total body movement.

Age 13 years and over:

By this age the teenager should be helping plan the exercise activities. The parents, teen, and staff can talk together about what the teen likes to do and what muscles need strengthening and what joints need extra moving.

CLAY PLAY FOR WEAK HANDS



roll the clay
but be sure to
keep the fingers
spread apart

1. make a big roll of clay
2. put it into palm of hand
3. Squeeze!

1. make a ball of clay
2. squeeze it flat between every two fingers

1. put a ball of clay between thumb and first finger
2. squeeze the ball until flat
3. repeat between thumb and each finger

1. first put the fingers close together
2. now put a ring of clay tightly around them
3 now spread the fingers apart as far as you can

use both of the positions you see at the left

1. make a flat plate of clay
2. put finger tips all together in the center
3. now spread your fingers out like the picture shows

16

ACTIVITIES DONE IN DAILY LIVING

We all use joints and strengthen our muscles by the things we do every day from the time we get up until we go to bed. Therefore, we have included on the next few pages things you can encourage your child to do every day that will give good exercise and help prevent hurting swollen joints. All these things are usually helpful, but it is not necessary to force the child to strictly stick to these ways of doing things. If life becomes unpleasant, a constant battle between you and your child, you may be doing more harm than good. Activities in daily living that are especially important to follow will be explained to you and the child.

In The Bathroom

Squeeze your washcloth or the sponge. Don't wring it!

Getting Dressed

Rather than call for help, use long handle shoe horn, snaps on shirts, zipper pull, elastic shoe strings. Give yourself lots of time to get dressed.

Drinking

Use both hands to hold your cup or glass and *spread* your fingers around it.

Shoes

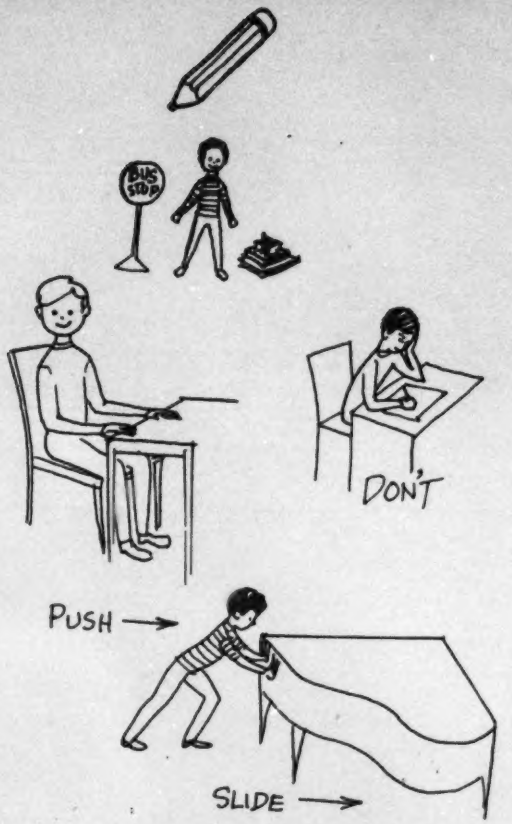
Well made ankle high tennis shoes (Converse, Keds, Adidas) are the best shoes for you if you have knee, ankle or foot joints that swell. They help stop jarring of your ankles and foot bones, and they fit even if your ankles or foot joints swell.

Let's Walk

Heel, toe and away you go...
Walk with toes pointed forward, head up and WALK TALL. Bend your knee and hip.

Carry My Books?

How? Why not do as the mountain climbers and use a back pack. If you carry them in your arms, shift them often. If you use a school bag with a handle, move it from left hand to right often.



Writing

Use a fat pencil or fat pen if the thin ones are hard to hold.

Waiting With A Load

Put your books or heavy packages down instead of holding them.

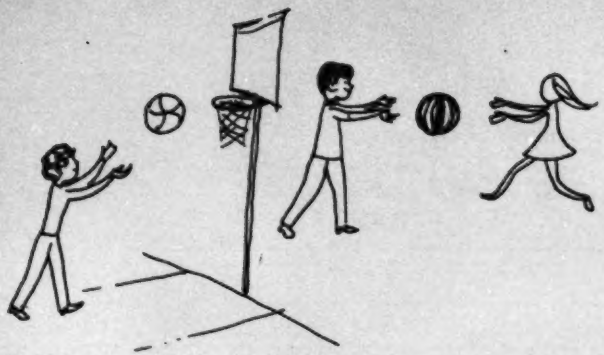
Sitting Still

DON'T lean your head on your hands. Sit in a comfortable chair with both feet on the floor. Sit with your back against the chair. When you're ready to get up, push down on the seat of the chair with the palms of both hands.

Moving Something?

Push with your palms rather than pull.
Slide heavy things, don't lift them.

19



Play

Hands need motion to thrive...

Play games where you grasp and let go of the object, NOT just hold it. Ball games are good.

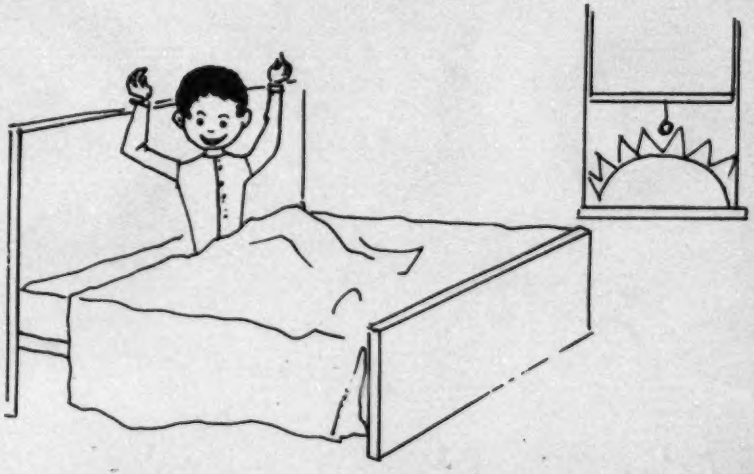
Use your wrists to lift, not just your fingers.

Rest periods... tired muscles do not give your joints the support they need. Holding one position makes the muscles tired.

Bed

Your bed needs a firm mattress.
No pillow is best, but a small flat one is O.K.

You will wake up in the morning better able to do all the things you want to do!



SPECIAL EXERCISE PROGRAM - PHYSICAL THERAPY

"I can't stand the fighting about exercises."

Most adults realize the need to exercise daily. How many times have you promised to exercise 10 minutes every day and failed? Children are human, too; nothing that is hard to do, painful, or boring is very exciting even if the child knows "it is good for you."

Here are some hints from other parents:

1. Explain it is "good" because a) it makes muscles strong
   b) it prevents or corrects deformities.
2. Make games out of the exercises.
3. Have the whole family do the exercise; exercising alone is no fun.
4. Exercise in front of a mirror if alone.
5. Don't rush when doing exercises with your child; let your child know that you have the time and want to help.
6. Bathing or swimming for 15 minutes before exercising often helps loosen stiff muscles.
7. Praise the child for doing such a hard thing.

21

SPLINTS

When joints become very weak, swollen, or painful, they sometimes need more support than the the body's muscles can give. If this extra support is needed a splint made of plaster or plastic will be prescribed for your child.

The splint may be prescribed:

1. only to wear at night to help keep the joint from going into a bent position
2. only to wear while doing certain activities
3. only to wear to help exercise the joint and stretch the muscles that move the joint

No splint should be worn 24 hours a day. All splints need to be removed at least once a day so the joint can be moved without the extra support. This helps strengthen all the muscles and lets the joint move into all its normal positions.

The fit of the splint is very important. A splint is fitting wrong if it causes:

1. more pain in the joint when it is worn than when it is not worn
2. obvious spasm or cramping of the muscles above or below the joint in the splint

REMEMBER:

If a splint is ordered for your child, be sure you understand:

1. exactly when the splint is to be worn
2. exactly how to put the splint on
3. signs that show the splint does not fit

Call if there are ANY doubts in your mind about the splint fit or how to use it.
Bring the splint along to EVERY clinic visit.

SLIT-LAMP

NOT

VISION TEST

EYE CARE

For some unknown reason, JRA sometimes causes a problem in the child's eyes. The jelly-like fluid in the eye, just behind the pupil (black spot) gets irritated. This problem starts WITHOUT any signs of pain or poor sight. It is serious because it can cause blindness but with prompt therapy this may be prevented. The aspirin your child takes *cannot* prevent this eye problem. A simple eye test that is painless can spot problems before any sight is lost. The name of the test is SLIT-LAMP examination.

For good eye care:

1. do the SLIT-LAMP test at least once a year; some children need testing every 6 months
2. have the test done at any eye clinic or by an eye doctor who is an M.D. (ophthalmologist) NOT by a person who only fits glasses (optometrist) or the school nurse
3. any time your child has any eye problem see an ophthalmologist *not* your family doctor
4. after the child stops medication for JRA, this test should still be done once a year for 4–5 years – eye disease can develop even if the joint disease seems to be gone
5. whenever you need eyes tested for glasses tell the eye doctor that the child has JRA and ask for a SLIT-LAMP test

DIET

There is NO known food or vitamin that causes or cures JRA. However, we do know that a child who has 3 well balanced meals a day has the most energy to play and to learn. Also we know that children who are overweight are less active than normal weight children. Since a child with JRA has to stay active, it is important that you try to help the child get 3 normal meals a day. If you need help in deciding what amounts of food and types of food your child needs, please let us know. We will measure height and weight at each clinic visit so you will know if your child is growing normally.

FOUR COMMON FAMILY AND SOCIAL PROBLEMS

Problem #1: "This child has to go through so much every day!"

It is normal for parents to not want to see their child suffer, but FEELING GUILTY IS WRONG. YOU DID NOT CAUSE the JRA and you are working with medical staff to control it. Feeling guilty usually leads to treating the child "Special" and that causes many more problems!

Try to treat your child normally; "they do much better on their own than you would ever guess."

Problem #2: "His brothers and sisters are always picking on him."

Often this happens because the child with JRA is being treated as "Special" or his siblings think he is getting extra privileges because he has JRA. Therefore:

(1) Be sure the child with JRA has some home chores to do. Not giving attention to every ache and pain of the child with JRA can also help prevent other children in the family from trying to get attention by complaining about little pains.

(2) Instead of you helping the child with JRA do things he really needs help with, let one of the other children help him.

Problem #3: "Four times a day we fight about Aspirin."

Age 1–4 years often start spitting Aspirin.

1. Try changing from baby to unflavored adult Aspirin.
2. BE FIRM – this is not a new game you are playing.

Age 6–12 often say they took their Aspirin but really were "too busy" or "forgot."

2. BE FIRM – they may feel fine but they still need the Aspirin.

Age 13–17 do not want to be "hassled."

1. Allow them some or all responsibility to take the aspirin.
2. Make them see medication taking as an "adult's job" ie: If they are adult they will do it correctly.
3. Let the medical staff talk with the teen if you know the medication is being done wrong.

Problem #4: "The school is always sending my child home; they say she needs to be in a special school."

Most children with JRA have their biggest problems in school. School staff have probably never had a child with JRA before; they often are frightened of hurting your child or pushing the child too much. You should expect that your child can go to a regular school and will not miss a lot of days.

You should: 1. go to school and meet the teachers to explain JRA and your child's treatment program.
2. have your medical staff contact the school.

Explain to the school principal, teachers, *and* nurse:

1. JRA is not contagious even if your child has the kind with rashes and fever.
2. Try not to treat the child as "Special."
3. When your child says he is "sick," usually just lying down to rest a few minutes will help a lot.
4. Stiff, swollen joints move slowly so extra time is needed to change class, write, get dressed, etc.

5. Stiffness is usually worse in the morning. Some days the child may come late.
6. Mild to moderate exercise is good!
7. Taking Aspirin at lunch time is as important to your child as insulin is to a diabetic child.
8. Be sure the nurse or teacher watches your child swallow the Aspirin.
9. There is NOTHING wrong with the child's mind. (They may need to take work home if hand joints are a problem.)
10. Give school personnel the name of the Arthritis Clinic, phone number, and staff person to contact if they have questions to ask.

These are the four most common problems families have had. Be sure to call your medical team when you are having troubles. Often there is a person whose special job is to get you help and talk problems out.

WHEN YOUR CHILD SEEMS TO BE WELL

After the JRA appears to be gone (remission) the medication will slowly be reduced to the point that the child will probably not need any medicine. At first we will still want to see the child every few months to be sure the JRA is not coming back. If all the joints remain normal and the child seems to be free of pain, the visits will probably be cut down to once a year.

IT IS IMPORTANT FOR THE DOCTOR TO SEE YOUR CHILD AT LEAST ONCE A YEAR FOR 4 -5 YEARS AFTER THE JRA IS GONE.

CALL if your child has:

1. any new swollen or stiff joints
2. walks with a limp; or any other change in the way the child walks
3. seems to be much less active for no known reason
4. if you, as the parent, have any new concerns.

This booklet may not have covered all the areas of questions and knowledge you want it to. There is much more to know about how JRA might effect growth, what can trigger flare-ups, and what research is being done to find causes and cures for JRA. These topics will be covered in JRA Parents' Classes and at clinic visits, but, please, call whenever you have questions or any problem.

REMEMBER: WORKING TOGETHER WITH YOU is the best way we and you can help your child.

Phones: Weekdays:

Evenings:

Weekends: